

**MINUTES
of the
THIRD MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**October 22, 2015
State Capitol, Room 322
Santa Fe**

The third meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee was called to order on October 22, 2015 by Senator Nancy Rodriguez, chair, at 8:59 a.m. in Room 322 of the State Capitol in Santa Fe.

Present

Sen. Nancy Rodriguez, Chair
Sen. Craig W. Brandt
Rep. Miguel P. Garcia
Sen. Linda M. Lopez

Absent

Rep. Tim D. Lewis, Vice Chair

Advisory Members

Rep. Deborah A. Armstrong
Sen. Gerald Ortiz y Pino

Sen. Ted Barela
Rep. Nora Espinoza

Guest Legislator

Sen. William P. Soules

Staff

Shawn Mathis, Staff Attorney, Legislative Council Service (LCS)
Michael Hely, Staff Attorney, LCS
Nancy Ellis, LCS
Diego Jimenez, LCS
Erin Bond, LCS

Guests

The guest list is in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file.

Thursday, October 22

Welcome and Introductions

Senator Rodriguez welcomed those assembled and asked legislators and staff to introduce themselves.

Centers for Independent Living

Ronald I. Garcia is executive director of New Vistas, a nonprofit center for independent living that supports a nine-county service area in northern New Mexico and provides advocacy, independent living skills training, peer support and information and referral for disabled individuals. The new federal Administration for Community Living has added three additional core responsibilities: assistance with youth transition; assistance to individuals wishing to remain in the community instead of moving to a nursing home; and assistance to disabled individuals residing in a nursing home who wish to return to the community. Mr. Garcia noted that there is no additional funding allocated to develop and implement these new services. Currently, New Vistas centers offer early childhood intervention programs, benefits advocacy and consumer/family and one-on-one assistance to approximately 550 children and families and 200 individuals with disabilities and also offers another 2,000 individuals information and referrals. Declining rural populations mean declining services, Mr. Garcia said, and lack of choices in housing, transportation, education and health care are major issues for people living in rural and frontier areas. He urged legislators to consider investing more to provide better community-based support for New Mexicans with disabilities.

Albert Montoya, executive director of the Ability Center for Independent Living based in Las Cruces, told subcommittee members that his organization serves a six-county area of southwestern New Mexico. Mr. Montoya said that, for many persons with disabilities, community barriers can severely limit choices of where to live, work and travel and how to spend leisure time. A center for independent living (CIL) is a nonprofit, consumer-controlled, community-based organization that provides an array of independent living services (see handout), and Mr. Montoya provided a series of case histories that highlighted these offerings. Independent living is considerably less costly than nursing home care, he said, and peer support and numerous social events make a CIL feel more like home.

Sue Hagler described programs of the Independent Living Resource Center in Albuquerque, which include the provision of information and advocacy for housing, benefits, transportation, education and employment for individuals with disabilities. Ms. Hagler, who is disabled, said that the Independent Living Resource Center is part of a movement for change in communities so that people with disabilities can live and work in a barrier-free society. The center, with two locations in Albuquerque and other locations in Socorro and Alamogordo, collaborates with providers to secure home modifications and to obtain housing by providing financial aid for first and last month's rent, deposit and household items. A center co-worker, Kate Unna, who also is disabled, described her efforts to encourage other disabled individuals to find meaningful employment, especially individuals in their twenties and thirties like herself.

She educates disabled individuals about the process of getting off Social Security benefits and getting back to work. Ms. Unna is not a case manager, but said she ends up doing a lot of work that could be considered case management.

Branda Parker is director of the San Juan Center for Independence (SJCI), which is based in Farmington with satellite offices in Gallup and Albuquerque. Ms. Parker said that her nonprofit organization serves the northern pueblos and offers a consumer-directed program of local, state and national advocacy for systems, as well as individual self-advocacy; personal care services and nursing home transition; and youth transition services. A procurement program assists consumers in obtaining assistive devices for more independent lifestyles, and an alternative loan program provides loans through a bank partnership that offers lower interest rates. There are many classes and activities at the SJCI, including art, cooking, autism support, cat therapy, a consumer garden, peer mentoring, a summer youth program and recreational activities such as camping, fishing, rafting and skiing. An accessible sensory playground and Harmony Park provide entertainment and music therapy for consumers, Ms. Parker said. Utilizing an extensive network of collaborators, the SJCI is able to fill gaps where no services are available.

On questioning, subcommittee members and panel presenters discussed what legislators might be able to do to help independent living centers. Invest in children instead of prisons, one center director suggested, adding that it always comes down to money. Another presenter reminded subcommittee members that her center on the Navajo Nation is very rural, and there are no providers and no services available. Independent living centers are funded through a patchwork of federal, state and local grants and programs, the presenters said, and, because of sequestration, federal funding has been reduced to less than it was in 1983. Several presenters described ongoing problems with Centennial Care (CC) and managed care organization (MCO) computer systems that have created huge eligibility issues. The chair thanked presenters and offered help with needed legislation.

Project ECHO (Extension for Community Health Outcomes)

Sanjeev Arora, M.D., F.A.C.P., F.A.C.G., director of Project ECHO and professor of medicine at the University of New Mexico Health Sciences Center (UNMHSC), described extraordinary growth for Project ECHO in meeting its mission to democratize medical knowledge and get best-practice care to underserved people — Project ECHO now is being utilized for 46 disease areas at 63 major universities throughout the world (see handout). The original project began with hepatitis C, and with a desire to help rural primary care physicians in New Mexico become as good as an interdisciplinary team in treating hepatitis C, for which, in rural areas, there had been little access to care.

Dr. Arora described an ongoing University of Wyoming project that tackles problems with assistive technology (tablets and apps) for developmentally disabled (DD) students in rural areas. Utilizing the Project ECHO model, a team of specialists is joined in a weekly video conference with school teachers, students and even family members to improve teaching methods

and enable students to learn in their home communities. Project ECHO provides a tremendous opportunity to democratize the knowledge and best practices of the "super-specialists", he said.

Erika Harding, M.D., director of replication initiatives, Project ECHO, described the use of Project ECHO in early diagnosis and treatment of autism, which has the potential to save billions of dollars in long-term care costs. With primary care providers (PCPs) on the front lines of recognizing and initiating services, a pioneering Project ECHO program at the University of Missouri provides extensive multidisciplinary training for PCPs, connecting them with a team of experts for case-based learning. Dr. Harding said that this model is being replicated for autism care across the country and now includes locations in California, Arizona, Texas, Tennessee, Ohio and Pennsylvania. A pilot study utilizing Project ECHO will be launched in New Mexico in January 2016 to help address the extreme statewide shortage of providers of applied behavioral analysis, which is a highly effective method of treatment for children with autism (see handout). This model works even in India, where it now is being utilized, Dr. Harding said; there is no other way to bring specialists all at once to rural areas.

Martin G. Kistin, M.D., a clinical gastroenterologist and professor of medicine at UNMHSC, said that Project ECHO is the greatest advance in health care that has happened in his lifetime. In his many years of clinical practice, he was a specialist with a long waiting list and many patients who came from great distances. Some of them did not even have running water in their homes, and the time and the expense of transportation prohibited much treatment. When PCPs feel isolated, Dr. Kistin said, they do not remain in the community. If they feel supported and valued, this dynamic changes dramatically.

Each month, 80 people come to New Mexico from all over the world to train in the Project ECHO model, Dr. Arora said, and Project ECHO is an opportunity to transform care in rural areas at a low cost. Dr. Arora strongly urged legislators to increase funding to Project ECHO, noting that there is huge potential for the model to lead in the treatment of disabilities. Dr. Arora said he was scheduled to meet tomorrow in Washington, D.C., with members of the Obama administration, and later with representatives of the federal Health Resources and Services Administration and the Substance Abuse and Mental Health Services Administration, to discuss potential new roles for the Project ECHO model. MD Anderson Cancer Center at the University of Texas currently has seven Project ECHO projects in Uruguay and Zambia, and Harvard University and the University of Rochester are using Project ECHO for elderly individuals who are being treated at home. In asking for an increase in state funding for Project ECHO (to a total of \$5.1 million), Dr. Arora noted that the State of Missouri is providing several million dollars annually for just one Project ECHO program. Times are hard in New Mexico with the downturn in oil and gas revenue, but the cost savings to the state are enormous — estimated to be \$47 million in 2013 alone, Dr. Arora said.

Update on Self-Directed Waiver

Cathy Stevenson, director of the Developmental Disabilities Supports Division (DDSD), Department of Health (DOH), and Angela Medrano, deputy director of the Medical Assistance

Division, Human Services Department (HSD), described the medically fragile waiver (MFW) that provides home- and community-based services to DD individuals who are medically fragile and have a developmental disability or are developmentally delayed, or at risk for becoming developmentally delayed, and meet a certain level of need criteria (see handout). These services currently are delivered either through the traditional DD waiver (136 recipients) or through the Mi Via self-directed waiver (77 recipients). Ms. Stevenson and Ms. Medrano also provided handouts of historic information about the agency-based community benefits and self-directed community benefits. The MFW program expired on June 30, 2015, was to transition to CC on July 1, 2015 and is currently operating on an extension from the federal Centers for Medicare and Medicaid Services (CMS). The transition to CC was postponed, Ms. Stevenson and Ms. Medrano said, to allow more feedback from meetings with families and with the advisory board before proceeding with the complex transition.

Tim Gardner, legal director of Disability Rights New Mexico, described his agency's concerns with the fact that individuals who qualify for nursing home level of care are not given a comprehensive assessment but, rather, are assessed only on the 10 activities of daily living (see handouts). The problem is that individuals have to trade homemaker services for another category, such as physical therapy or cognitive rehabilitation therapy. Most people are not willing to trade out personal care services and, thus, forgo other needed services.

Cindy Padilla, a private support broker for Self-Directed Choices, LLC, said behavioral health services are available, but the assessment for this is not as robust as it should be, and individuals still would be required to trade out personal care hours to receive services (see handout). Budgets have been grandfathered into CC, Ms. Padilla said, but if there is any change to the budget, the grandfathered elements are no longer valid. The wages paid to providers in the budgets are different for each MCO, and as a consumer's health declines and more services are often needed, that, along with increased payroll taxes that come out of that budget, results in an even greater reduction in services. It is difficult to find part-time caregivers, she said, and there are issues with the mileage allowance for transportation, as well. Ms. Padilla said she participates in monthly meetings with the MCOs, which has been very helpful in resolving specific issues, but the overall program needs more work, she said.

Dave Murley, president and chief executive officer of AAA Participant Direction, pointed out discrepancies among the CC self-directed community benefit budget policy, the New Mexico Administrative Code, the Managed Care Regulations and the CMS Special Terms and Conditions. The state wanted to fix what it perceived as excessive budgets under the Mi Via self-directed waiver program, Mr. Murley contended, and the state created restrictions in its policy manual requiring consumers to reallocate personal care hours in order to receive other services (see handout). The actual cost of agency-based services is not available, he said, and because allotments are based on rates that "low-ball" the actual cost of agency-based services, budget amounts are insufficient for individuals to access services. Mr. Murley also criticized the lack of access to due process for appealing budgets, and he urged training in self-directed philosophy for

MCOs and agency personnel, as well as evaluation of the efficacy of different long-term care models.

On questioning, subcommittee members conveyed their concern about limiting categories of care, noting that these individuals appear to be short-changed on the assessment, leaving these individuals with no ability for self-direction. The subcommittee chair asked that all of the MCOs be invited to the next meeting to explain to members how budgets are created and to explain the process for appeal. Ms. Stevenson reiterated that the rollout of proposed changes for Mi Via self-directed waiver participants has been delayed until the 2018 Medicaid waiver negotiations.

New Mexico Developmental Disabilities Waiver Program Comparative Cost Analysis

Robert Kegel, advocate and principal of Robert Kegel & Associates, said that the recent settlement of the *Waldrop* lawsuit against the DOH substantiates his long-standing complaint that the state's use of the Supports Intensity Scale to determine the level of service needs for DD waiver recipients was actually intended as a way to cut services. Mr. Kegel also has long disputed the DDS's contention that DD waiver costs in New Mexico are among the highest in the nation, and he presented a detailed and lengthy analysis of rates for comparison disputing this (see handout). New Mexico's DD waiver is actually among the cheapest in the country when all factors are taken into account, he asserted. The DDS contractor's analysis concluding that New Mexico's rate was among the highest utilized a study that blended support waivers with comprehensive waivers that were never intended to be used for such a comparison. The CMS recently commissioned a report by Truven Health Analytics (see handout) that provided data in a more useful form so that a true comparison could be performed, Mr. Kegel said. He urged legislators to, in the future, carefully consider the source of any statistical data supplied by either the DOH or the HSD, or their contractors, regarding comparable waiver costs, as well as any potential conflict of interest that may exist. His report is not intended to be a conclusive study, but only a beginning, Mr. Kegel said. The DDS needs to identify other comparable states, practices and methods of service before recommending any changes in New Mexico.

Subcommittee members urged Mr. Kegel to provide all of his data and observations to the Legislative Finance Committee.

Recognition of Anna Otero Hatanaka

Senator Rodriguez read from a Senate Certificate of Recognition for Anna Otero Hatanaka dated October 16, 2015, honoring the long-time social justice advocate upon her retirement as executive director of the Association of Developmental Disabilities Community Providers. Over a span of 35 years, Ms. Hatanaka's efforts have led to increased state funding for home visitation, low-income child care, community corrections programs, developmental disabilities consumer programs, the Family Infant Toddler program and for aid to families with dependent children. The senate certificate, which will be duplicated in the house, further states that she played a major role in the passage of the State Use Act, which supports employment of those with developmental disabilities and has served as a valuable resource to legislators on helping find ways to support these individuals, their families and communities and those who serve them. Subcommittee

members each spoke to Ms. Hatanaka, saying she will be sorely missed and lamenting the loss of institutional knowledge with her retirement.

Many members of the audience, including Mark Johnson, Ms. Stevenson, Ms. Medrano, Mr. Garcia and Nat Dean, among others, also spoke in honor of Ms. Hatanaka and her lifetime of advocacy.

Minutes Approved

The minutes of the September 25, 2015 subcommittee meeting in Albuquerque were approved.

Adjournment

The meeting was adjourned at 4:48 p.m.